Frank Stephens

Quincy Jones Advocate, Global Down Syndrome Foundation Board Member, Special Olympics Virginia Before Subcommittee on Labor, Health and Human Services, and Education Committee on Appropriations U.S. House of Representatives October 25, 2017

Mr. Chairman and Members of the Committee, it is an honor to be here today as part of this panel. Just so there is no confusion, let me say that I am not a research scientist.

However, no one here knows more about life with Down syndrome than I do. If you take nothing else away from today's hearing, please remember this, I AM A MAN WITH DOWN SYNDROME AND MY LIFE IS WORTH LIVING.

Why do I feel the need to make that point? Across the world, a notion is being sold that maybe we don't need to continue to do research concerning Down syndrome. Why? Because there are pre-natal screens that will identify Down syndrome in the womb, and we can just terminate those pregnancies. In places as wide-spread as Iceland, Denmark and South Korea, government officials have proclaimed that these government encouraged terminations will make them "Down syndrome free by 2030."

It is hard for me to sit here and say those words. Let's be clear, I completely understand that the people pushing that particular "final solution" are saying that people like me should not exist. They are saying that we have too little value to exist.

That view is deeply prejudiced by an outdated idea of life with Down syndrome. Seriously, I have a great life. I have been a guest lecturer at major universities. I have contributed to a best-selling book, had a feature role in an award-winning film, guest starred on an Emmy winning TV show, and spoken to thousands of young people about the value of inclusion in making America great. I've even been to the White House twice, and I didn't have to jump the fence either time.

Seriously, I don't feel I should have to justify my existence, but to those who question the value of people with Down syndrome I would make three points.

First, we are a medical gift to society. As you have heard, our extra chromosome makes us a blueprint for medical research that could reveal answers to cancer, Alzheimer's, and Immune System disorders. If not for us, then for you and the one's you love, fund this research.

Second, we are an unusually powerful source of happiness. A Harvard based study has discovered that people with Down syndrome, as well as their parents and siblings are happier

than society at large. I know happiness is not something you can assign dollars to, but surely it must be worth something.

Finally, we are the canary in the eugenics coal mine. Genomic research isn't going to stop at screening for Down syndrome. It won't be long before we can identify all manner of potentially expensive medical or personality "deviations" in the womb. As a society, we have an opportunity to slow down and think about the ethics of choosing which humans get a chance at life.

Let me just repeat what I said. We are helping to defeat cancer and Alzheimer's and we make the world a happier, kinder place. Is there really no place for us in this society? Is there really no place for us in the NIH budget?

On a deeply personal note, I cannot tell you how much it means to me that my extra chromosome might lead to the answer to Alzheimer's. It is likely that this thief will one day steal my memories, my very life, from me. This is hard for me to say, but it has already begun to steal my Mom from me. Please think of all those people you love the way I love my Mom. Help us make this difference.

Let's be America, not Iceland or Denmark. Let's pursue answers, not "final solutions." Let's be America. Let's pursue inclusion, not termination. Let's make our goal to be Alzheimer's free, not Down syndrome free.

Thank you.